

Exploratory Study of Factors that Influence Parental Adaptation during the Autism  
Spectrum Disorder Diagnostic Process

Josephine de Deuge

School of Medicine

University of Tasmania

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I, Josephine de Deuge, declare that this report is my own original work and that  
contributions of others have been duly acknowledged.

Signed .....

Date.....

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**An Exploratory Study of Factors that Influence Parental Adaptation during the  
Autism Spectrum Disorder Diagnostic Process**

Josephine de Deuge

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## **Abstract**

Due to the complexity of diagnosing Autism Spectrum Disorder (ASD) a multidisciplinary diagnostic approach represents best practice quality care. This process can however be time consuming, with parents often facing long waiting periods which may complicate adaptation. The current research investigated the experiences of mothers who have had their child diagnosed through the multidisciplinary team at St Giles, Tasmania. Four mothers partook in semi-structured interviews, to describe their experience of the ASD diagnostic process. A qualitative approach was adopted and data analysed using thematic analysis. This investigation identified the issues that parents face throughout the three stages of the diagnostic process; pre-diagnosis, diagnosis and post diagnosis and the organisational factors that may positively influence how parents adapt to these issues. The results were fitted into a model showing that factors within the St Giles diagnostic process may interact to facilitate positive adaptation by influencing parent's social support and their perceptions of the situation or Sense of Coherence (SOC). This report provides a valuable insight into parental experiences of the diagnostic process and receiving a diagnosis of ASD. It also highlights the complexity of this process and, implications for further research and practice.



## **Autism Spectrum Disorder (ASD)**

ASD is a neurodevelopmental disorder characterized by delayed and atypical development of social communication and interactions. It can also present with behaviour patterns that are restricted and repetitive with onset occurring in early childhood (American Psychiatric Association, 2013; Poslawsky, Naber, Van Daalen & Van Engeland, 2014). Prior to the release of the current diagnostic and statistical manual of mental disorders (DSM-5), the term of ASD was used as an umbrella term encompassing Autistic disorder, Asperger syndrome, and Pervasive Developmental Disorder not otherwise specified (PDD- NOS). However, within the DSM-5 these separate classifications were integrated to form the one diagnostic term of ASD with three levels of severity (American Psychiatric Association, 2013).

Although ASD is one of the most prevalent childhood disorders, with an approximate 1 in 106 or 0.94% prevalence rate among Australian children (Veness et al., 2012) the cause remains unknown. Also due to the spectrum of the disorder with the various severities and presentations as well as there being no certain prognosis upon receiving a diagnosis, the diagnostic process and subsequent diagnosis can be met with great uncertainty from parents (Mulligan, MacCulloch, Good & Nicholas, 2012).

## **The Issues Faced by Parents**

The effects of having a child diagnosed with ASD are well documented in the literature. Research has shown that parents of children with ASD experience various degrees of strain and distress (Falk, Norris & Quinn, 2014). They also have a

significantly higher risk of mental health problems compared to parents of typically developing children and even higher than parents who have children with other types of disabilities, such as Down syndrome (Dabrowska & Pisula, 2010). There are a number of different reasons that could contribute to the high level of mental health issues faced by these parents. These factors include feelings of loss and grief over changing expectations for their child's future and their own, feelings of isolation, and diminished social relationships due to their child not fitting into social norms (Myers, 2009). This decrease in social engagement is also due to the stigmatization that parents face which they may commonly feel in public situations (Gray, 2002). Having a child diagnosed with ASD has also been shown to be linked to decreased marital satisfaction (Roger, 2008), as the parents tend to focus their energy on their child.

Though the negative impacts of having a child diagnosed with ASD are well recognized, the fact that studies (Weiss, MacMullin & Lunskey, 2014) have found diversity in parental reactions and adaptation to having a child diagnosed, suggests that there are factors that may be protective against the accumulation of such stressors and help to influence coping strategies to facilitate positive adaptation. Through the identification of these factors, this knowledge can inform the development of strategies to assist parental adaptation and identify those who may be more at risk to ensure they get additional support.

Facilitating positive adaptation for parents is crucial in the area of ASD, as not only can mental health issues of parents have direct negative impacts of themselves, but they can also have secondary impacts on their child. A study by Moore (2009) looked at parent's likelihood of adhering to treatment recommendations of their child, and found that parents were less likely to adhere to

behavioural treatment recommendations as compared to medical treatments.

Suggested reasons for this include the emotional challenges attached to adhering to behavioural management programs for children with ASD which can be even harder to implement when the parent is dealing with a mental health issue. This suggests that having a mental health issue may negatively impact a parent's ability to implement and stick to programs which can potentially benefit their child.

Positive adaptations of parents have also been shown to have positive effects of parent-child interactions. A study by Watchel and Carter (2008) found mother were more emotional resolved regarding the diagnosis had significantly better interactions with their child. They had higher cognitive and supportive engagement in play as well as increased attention to activities and greater reciprocity and mutual enjoyment. Not only can better interactions with their child improve the child's social interactions, but behavioural symptoms and severity of the child are also highly correlated with maternal stress (Duarte, Bordin, Yazigi, & Mooney, 2005).

### **Factors that Influence positive Adaptation for Parents**

Numerous studies (Boyd, 2002; Bristol & Schopler, 1983; Falk, 2014) have examined factors that may influence adaptation, including social support, autism severity symptoms and the dispositional characteristics of the parent. However the majority of research into adaptation has done so using partial analysis of variables. Meaning that research has looked at how one factor influences adaptation such as social support whilst controlling for another such as ASD severity of the child. However due to the complexity of the disorder it is necessary to adopt a

multidimensional and holistic approach to examine the influences of multiple variables simultaneously.

### **The Double ABCX Model of Adaptation and Adjustment**

One of the ways this has been done is by using the Double ABCX model (McCubbin & Patterson, 1983) of adaptation and adjustment. This model has been used to understand how parents adapt to a stressor through resources such as social support and parents perception of the situation or their beliefs in their ability to deal with the situation. This model has been found to be useful in multi-dimensional analysis of stress and adaptation in families who have had a child diagnosed with ASD (Pozo, Sarria & Briso, 2011).

Social support is a major factor within this model and has been shown in numerous studies to influence how parents adapt. Boyd (2002) conducted a critical review of the effect of social support on the impact on stress in mothers who have a child diagnosed with Autism. Their finding that social support could be a protective factor against stress and mental health problems echoes the earlier findings of Gray and Holden (1992).

Gray and Holden (1992) looked at the factors which contribute to the psychosocial well-being of parents of children with ASD. The study found that parents who had higher levels of social support had lower levels of depression and anxiety compared with those parents receiving less social support. Their study also showed that parents who had lower levels of social support also has reported higher levels of anger. They believed this could be due to those who have lower levels of

social support being less likely to engage in social activities and community-based events which can be beneficial in reducing stress.

The Double ABCX model also looks at parental adaptation in terms of how Sense of Coherence (SOC) affects outcomes. This refers to a parent's belief in their ability to cope with the stressor. A person with a higher level of SOC will be less likely to perceive a situation or circumstance as threatening, and instead be more likely to see that the situation as manageable (Antonsky & Sagy, 1986). Studies such as Bristol (1987), and Pozo and colleagues (2006) demonstrated that SOC can play a protective role against stress and promote more positive adaptation by protecting the psychological and social well-being of parents. In order to optimize the chances of successfully coping with a stressor one must believe that they sufficiently understand the problem and that they have the resources available that are needed to cope with the issues.

It is suggested that SOC may be able to be developed over time. This can be done by increasing parent's knowledge of the stressor and empowering them to increase their perception of having a greater ability to manage the situation (Pozo et al., 2011). However, because of the novel challenges that a parent may be presented with, due to the prospect of an ASD diagnosis, the quality of adaptation will also be influenced by the support received from formal health and mental health resources (Bristol & Schopler, 1983). Given the diversity of characteristics likely to prevail in the parent child relationship, an important issue in this context is the degree to which formal support can be tailored to family-child needs in ways that facilitate long-term adaptation in the latter. A construct that assists understanding this dynamic relationship is empowerment.

Empowerment complements SOC in the sense that they are both concerned with gaining control in ways that facilitate adaptation, with the empowerment including the perspective of how external sources, such as organisation support and resource can influence capability (Banach, Iudice, Conway & Couse, 2010). Parental empowerment refers to the development of knowledge and skill as well as feelings of self-efficacy and beliefs in their ability to take control over their lives (Shulman, 1992). For example Mulligan and colleagues (2012), identified that pre-diagnosis parents described feeling powerless due to uncertainty regarding their child's behaviour, misconceptions about ASD, and unease over lengthy assessment and wait times. These feelings were briefly alleviated at diagnosis as parents felt their questions had been answered and believed that the diagnosis would facilitate access to resources. This poses the question as to whether empowerment and SOC can be facilitated through the diagnostic process by providing parents with knowledge and the relevant resources needed to exert some control during the initial stages.

Though the Double ABCX model has been found useful in demonstrating parent's process of adaptation, it does neglect the impact of factors throughout the diagnostic process that may influence this and may assist in positively influencing parental adjustment. Due to the complexity of the ASD diagnosis it is important to look at the entire process and factors that may interact in order to gain a full understanding of how parents cope with the situation. Looking throughout the entire diagnostic process is also important as most research which looks at parental adaptation focuses on the post-diagnosis stage, however as Mulligan and colleagues (2012) found adaptation needs to occur throughout the entire process, including during the period awaiting assessment. It was found that the 'waiting, worrying and uncertainty' in the pre-diagnosis stage may complicate adaptation, as in some cases

ASD is suspected, however families felt ill-equipped and perhaps disempowered to move forward without professional guidance and therefore feel as though they are in limbo. This demonstrates the need for parents to be provided with appropriate resources and support during this stage of the process.

In order to understand how the diagnostic process can be used to facilitate positive adaptation, the issues that parents face throughout this process need to be identified. Research suggests that when a child goes through the diagnostic process, there appears to be four distinct stages in understanding adaptation; pre-diagnosis, diagnosis, post diagnosis and overall acceptance and adaptation (Howlin & Moore, 1997; Smith et al., 1994). Research (Mansell & Morris, 2004) shows that throughout each of these stages parents face different issues which may interact and leads to implications with their overall adaptation to the diagnosis. Therefore each of these areas needs to be explored to identify the issues parents face and their needs during this stage.

### **The Diagnostic Process**

In Tasmania there are a number of different ways that a child can be diagnosed with ASD, including through a Paediatrician, private providers, the Tasmanian Health Service Autism Diagnostic system or through Psychologists employed by the Education Department. ASD cannot be measured by blood tests or non-invasive technology, and as such behavioural assessments are the only available means of diagnosis (American Academy of Paediatrics, 2001). However, all behavioural assessments are vulnerable to the issues of subjectivity and interpretive bias. The best way to minimise the risk of inaccurate diagnosis is by using a

diagnostic method that is evidence-based. Research has shown that in order to minimise subjectivity, Assessors should implement a number of different tools as well as using the skills of different professionals through a multi- disciplinary team diagnosis (Huerta & Lord, 2012).

A multidisciplinary disciplinary team consists of multiple professionals often including a psychologist, speech pathologist, occupational therapist and at times a medical professional. The team make the diagnosis through accessing behavioural information such as observations, formalised assessment measures, historical and developmental information, medical reviews and the reports of parents through interview (Falkmer, Anderson, Falkmer & Horlin, 2013). Though research has found that this process is one of best in terms of diagnostic accuracy, this process is costly, lengthy and time consuming and can put parents on a long wait list which creates a degree of uncertainty and stress for parents knowing that something may not be right with their child, but not having any resources to cope with this (Falkmer et al., 2013).

**Pre-diagnosis.** The pre-diagnosis stage refers to the stage before parents receive the diagnosis. This stage is often characterised by concern regarding their child's behaviour, however, confusion and denial can often come with this. Research (Howlin & Moore, 1997) shows that this period is often long and stressful for parents who are often put on long waiting lists. Howlin and Moore (1997) were the first to look at the experience of parents through the ASD diagnostic process. This was done through the use of surveys which were conducted on families in the United Kingdom. The results from this study found that over a quarter of parents waited more than five years from their initial concern before having a diagnosis confirmed.



One of the reasons for this delay as noted within the literature (Ahern, 2000), is that the physicians may not acknowledge the deficit in behaviour but instead put them down as something the child will ‘grow out’ of. Within an Australia study, Barbaro and Dissanayake (2009), identified that 50% of parents who had a child diagnosed with ASD were initially reassured that their child’s behaviour was normal. This study also found that the average time between when a parent had their first concerns about their child’s behaviour and the time it takes to obtain an ASD diagnosis is almost 4 years.

These delays in diagnosis contribute to parental distress and difficulty in coping with the behaviours (Goddard et al., 2000) due to the high levels of concern and uncertainty. These delays also result in parents and children missing out on the benefits of early interventions which can help to maximise the developmental outcomes for the child, but also assist in minimising parental distress (Barbaro & Dissanayake, 2009).

**Diagnosis.** The diagnosis stage refers to the period of the parent and child going through the assessment process and receiving the ASD diagnosis. When a child is diagnosed by a multidisciplinary team the assessment process can span over a number of weeks and consist of multiple appointments and conclude with a diagnosis being given by the team. Braiden, Bothwell and Duffy (2010), identified that during this stage parents can have issues with the complexity of the diagnostic process as it often involves a number of tasks which may evoke stress in parents, such as seeing their child struggle with tasks, as well as the stress of seeing multiple professionals after being referred from their GP. There is also the ambiguity of the diagnosis given (Skellern, McDowell, & Schulter, 2005) which can be confusing for parents. This is particularly the case for those who have little understanding of ASD.

Once the family receive a diagnosis they then have to accommodate this diagnosis into their life.

**Post diagnosis.** The post diagnosis stage refers to the period after the diagnosis has been given when parents are adjusting into life with a child with ASD. Although receiving a diagnosis can be extremely beneficial for parents as it allows the family to be able to understand their child's deficits and help them to seek appropriate intervention (Mansell & Morris, 2004). This process does however also have a number of issues such as parents experience grief upon being given a diagnosis of their child, and the realisation that their child is not 'normal' (Myers, 2009). It also involves a lot of practical issues such as parents seeking the appropriate interventions and therapies for their child as well as trying to maintain their other personal and family responsibilities.

The issues above demonstrate some of the challenges parents go through having their child officially diagnosed with ASD, and suggest that these stages are also important in influencing parent's overall adaptation.

### **Purpose of the Study**

Literature exists providing recommendations to more positively facilitate the adaptation to an ASD diagnosis (Mansell & Morris, 2004), as well as the personal factors individuals may utilise to assist their adaptation. However, there is a limited body of evidence identifying how diagnostic services can be used to facilitate positive parental adaptation and how these strategies interact with parental and family resources. This study analysed the experience of mothers who have had a

child assessed by a local multidisciplinary team (Developmental Assessment Team at St Giles) and received a diagnosis. The aim of this study was to identify the diagnostic process and procedural factors of a multidisciplinary assessment of ASD that influence parental adaptation. This study also looked at how these procedural factors influenced parental and family resources to develop a multidimensional understanding of parent's adaptation to having their child diagnosed with ASD. This study is important as variables that affect the diagnostic process are crucial to understanding parental experiences when they receive a diagnosis of ASD for their child, especially if these resources can be used to assist the experience of parents who are going through a multidisciplinary assessment.

### **St Giles, Tasmania,**

The St Giles Developmental Assessment Team (DAT) is a multidisciplinary diagnostic service located within Tasmania. DAT assessments are guided by best practice principles (McClure, MacKay, Mamdani & McCaughey, 2010), with assessments generally consisting of parental interview, childcare observations, Autism Diagnostic Observation Schedule- 2 (ADOS2) assessment, developmental assessment and a number of questionnaires including one on adaptive functioning and the other a sensory profile, concluding with a face to face feedback session. Though this type of diagnosis presents the most accurate diagnostic process the thoroughness of this assessment does however present as costly and time consuming, with no research suggesting this process facilitates positive adaptations of parents.

The research project was initiated by St Giles in an effort to improve efficiencies in service delivery. This is done in the hope that there can be

development of strategies that can be used by both this and comparable services in supporting parental adjustment to their child's diagnosis of ASD. As well as better supporting parents through all phases of the assessment process whilst keeping waitlists for services manageable. As this study is exploratory in nature with no previous research having looked at factors within a multi-disciplinary diagnosis and how these could influence parental adaptation a qualitative approach has been adopted.

### **Qualitative Research**

A qualitative method has been chosen to investigate this area due to the unexplored nature of the research as well as the complexity of the issue. A qualitative approach aims to describe and categorize data (Elliott, Fischer & Rennie, 1999) and is a useful way of identifying and describing the human experience which cannot be measured or observed (Patton, 2002).

A qualitative approach is also beneficial for this study as it allows the researcher to investigate multifaceted concepts such as world views, and for understanding the processes of adaptation and development in family settings (Miles & Huberman, 1994). Due to the large range of factors, interacting variables and contexts in which people get diagnosed, a qualitative study is initially needed to more clearly articulate the issues and relationships involved so that these can be quantitatively measured later if needed. Due to the subjectivity of qualitative data it needs to be analysed in a procedural manner in order to develop results that are meaningful and objective, thus thematic analysis will be used.

## **Thematic Analysis**

Thematic analysis was chosen for the analysis of this data as it can be done using an inductive ‘bottom up’ process. Meaning it allows the researcher to be able to code the data without it trying to fit into pre-existing ideas but instead theory development will be data driven (Braun & Clarke, 2006). This can be done using the systematic 6 phase process of thematic analysis developed by Braun and Clarke (2006). The process begins with phase 1, which involves immersing one-self in the data, which can be done by re-reading transcripts and re listening to interviews. Phase 2, involves generating initial codes for the data, or organizing data into meaningful group, where the data is categorized and labelled. In this phase the most important parts and segments of the data are pulled apart. Phase 3 involves searching for overarching themes within the data and is where the interpretation of the data begins. This is followed by phase 4, in this stage the researcher reviews the themes and examines how they support the data, as well as finding relationships within the data, which leads to the researcher generating a thematic ‘map’ of the data in phase 5. Phase 5 is also where the themes found need to be defined, lastly phase 6 which concludes with writing a report, where major extract examples will be chosen from the data to support themes and arguments.

The thematic analysis that was used within this this project was that informed by social constructionism. This method refers to understanding the meanings and constructions individuals attribute to situations and the involvements of agents and factors that influences these constructions in a social context (Tuckett, 2005). This method acknowledges that individual will have different meanings of objects and

therefore there is some level of subjectivity as there are alternate views of the world outside of objective explanations. This method has been chosen for this study as social constructionism allows an event such as having a child diagnosed with ASD to be viewed inside the social context of which it occurred allowing the researcher to look at all the interacting factors and how they influence the event (Tuckett, 2003).

## **Method**

### **Research Design**

Qualitative methodology was chosen as the approach to this research project due to its unique means of obtaining rich and meaningful data with a degree of complexity that cannot be achieved through quantitative analysis. The design implemented in this qualitative study follows the principles of Thematic Analysis (Braun & Clarke, 2006).

### **Participants**

Participants were mothers of children who had been diagnosed with ASD through the St Giles, multi-disciplinary team between 2010 and 2015. Four mothers responded and participated in a semi-structured interview. Three mothers had one child diagnosed with ASD and one mother had two children diagnosed with ASD. All children diagnosed with ASD were boys. Data was also collected from parents who had posted to online forums; Reddit and the Raising Children's Network regarding their experiences throughout the diagnostic process.

**Recruitment.** An initial invitation was sent out from St Giles to all the mothers who had had a child diagnosed with ASD between 2010 and March 2015. Mothers were contacted either by letter or email, and informed of the nature of the study and asked if they would be prepared to participate with details they could contact to arrange a time for interview.

Originally parents were split into three groups; those who had been diagnosed more than six months ago, those who had received a diagnosis within the last six months and those who were on the waiting list. The aim of this was to gain an understanding of parents concerns at that time. Due to the limited response rate of four participants the interview schedule was adapted to get participants to recall their memories at each stage.

Participants were also recruited by a StGiles Facebook post advertising the study. Once participants contacted the researcher a time was arranged for an interview as well as the researcher informing the participants of the study and answering any questions the participant may have.

**Material.** Material consisted of the recruitment letter (Appendix A); consent form (Appendix B); and information sheet which detailed the aims, requirements and benefits of the study (Appendix C); a digital voice recorder and N-vivo- 10 (A computer software package designed to help with management of qualitative data and coding); and an interview schedule which comprised prompts and questions for use during the interviews (Appendix D).

In order to increase opportunities to gain insight into parental accounts of their diagnostic experience and adaptation, a second approach to data collection was developed and included in the study. This involved collecting data from online forums. A strength of the latter was that it provided insights into the diverse nature of parental experiences.



## Procedure

**Human research and ethics.** Prior to study commencement, the Tasmania Social Sciences Human Research Ethics Committee granted approval of the study (Appendix E). An ethics amendment was sought to adapt the methods of recruitment by putting up an advertisement for the study on the StGiles Facebook page. A second amendment was sought after this to include data from online forums due to difficulties in obtaining sufficient participant numbers.

Once participants had arranged a time for the interview, semi-structured interviews were conducted by the student researcher. These interviews ranged from 25 minutes to 1.25 hours in length, and reflected participant's narratives, and in-depth exploration of experiences and events, and the interpretation and construction of meaning within these experiences. These interviews were conducted in person or over the phone depending on the preference and accessibility of the participant. Interviews were guided by a semi-structured interview schedule, although in keeping with a qualitative approach, the interviewer attended to, and was guided by, the interviewee. Hence interview questions were adapted according to the specific presentation of each interview which allowed deviation from the schedule and a natural conversational interview could occur. The questions within the interview were developed to elicit information regarding each participant's experience of the process and consequent adaptation strategies, with probes being utilised where appropriate. For example if a mother stated that she struggled with specific parts in the diagnostic process the interviewer would ask her to explain which parts she had struggled with.

Interviews were audio-recorded and transcribed verbatim. Following this they were sent to the participant for review and any alterations they may wish, with a requested two week turn around period, no participants requested alterations to be made. The transcribed interviews were then subjected to content analysis, assisted by N-vivo-10 qualitative management and analysis software.

Due to the limited response rate from participants, content regarding parent's experiences throughout the diagnostic process was also sourced from online forums; Reddit (Reddit.com) and the Raising Children's Network (Raisingchildren.net.au). The content that was accessed from these forums was selected based on the questions that were used throughout the interviews, and expressed parent's concerns and experiences throughout the diagnosis of their child. The data obtained from these forums was also analysed in N-Vivo-10. Due to the research question being focused on the process of a multi-disciplinary diagnosis, the data obtained from the online sources was not used to bring up new themes but used as a way to triangulate the data from the interviews and increase the validity of the research.

## **Data Analysis**

Transcribed interviews were analysed using Braun and Clarke's (2006) six-phase thematic analysis process. This process involved the researcher reading transcripts multiple times in order to maximise familiarity with the material. The data was then coded with the assistance of N-Vivo-10 qualitative software. This was done by extracting words, sentences or sections spoken by the participant that highlighted certain important concepts. Codes are a means of categorising sections of the data, which aids further analysis. The use of codes allowed the researcher to

highlight important statements, thoughts and meanings from the interview data.

Once the codes were developed the researcher used this data to link together codes and find relationships among the data which led to the cluster of themes and formation of thematic maps, which provided insight into important elements of parent's perception. Quotes were extracted from the data as supporting evidence for themes identified and discussed. All quotes referred to in the findings have been used in the same context as in the raw data.

## **Results**

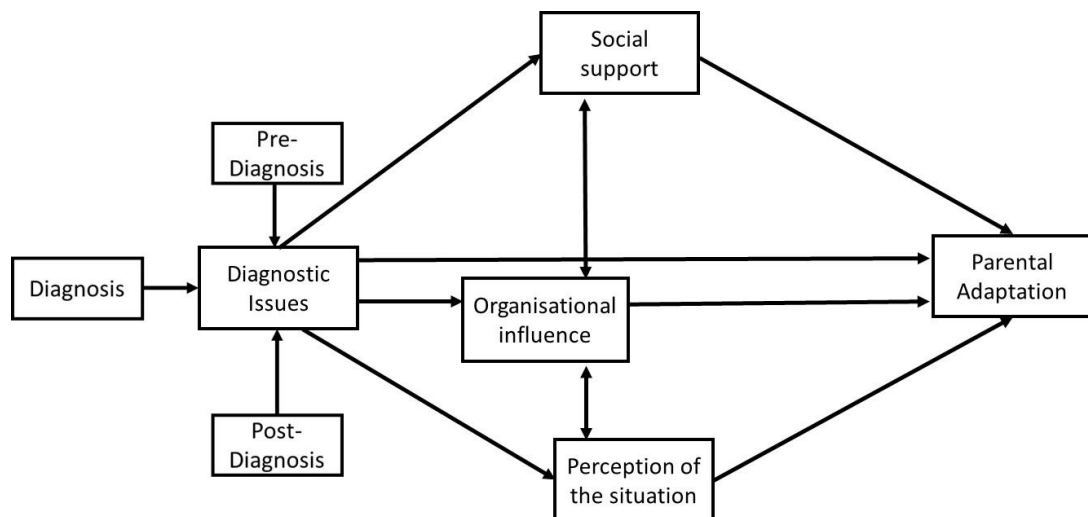
### **Thematic Analysis**

The purpose of this study was to identify factors that influence positive adaptation for parents during the process of having their child diagnosed with ASD. Themes were ascribed using N-Vivo-10 construct labels (using participant's own words). The analysis identified variables as well as relationships between variables. These will be discussed in more details below. To assist with ease of understanding, visual models and participant quotes are used to highlight each concept.

As a result of thematic analysis of the data, themes were identified relating to three stages within the diagnostic process: pre- diagnosis, diagnosis and post diagnosis. Figure 1 presents the overall model of adaptation. Each individual stage will be discussed leading to a further explanation of the model. Adaptive themes were then related to either organisational adaptive factors or personal adaptation factors which provided social support and/or influenced an individual's SOC and adaptation.

### **Reliability**

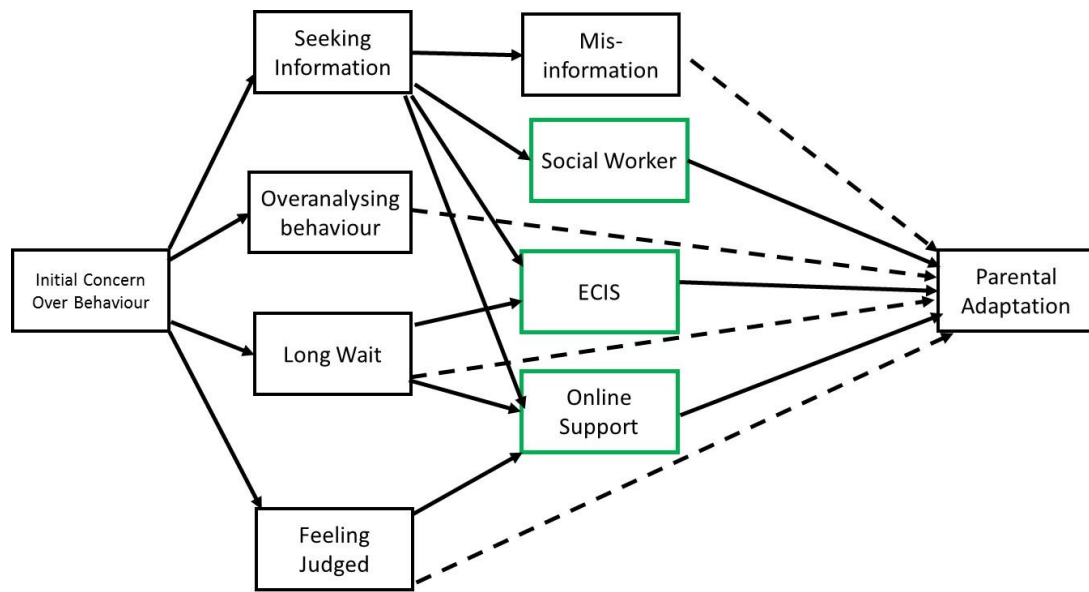
A section of transcript was additionally coded by a second independent coders and compared using Cohen's Kappa. A Cohen's Kappa of .59 was calculated which suggests a good level of inter-rater reliability (Landis & Koch, 1977).



*Figure 1.* Overall model for factors that influence parental adaptation during the ASD diagnostic process

The overall model of parental adaptation (see Figure 1) suggests that there are three different stages of the diagnostic process: pre-diagnosis, diagnosis and post diagnosis. Throughout each stage parents are faced with specific issues that can negatively influence adaptation. Parents adapt to issues that occur throughout the diagnostic process by utilising resources such as social support and their perspective of the situation. Parents also adapt using their (SOC) which refers to their beliefs in their ability to be able to cope with the stressor. The results suggest that these resources can be influenced by organisational factors within the diagnostic process to facilitate positive adaptation. These findings will be individually considered in the following sections.

## Pre- Diagnosis



*Figure 2.* Model of factors that influence parental adaptation during the pre-diagnosis stage. Green boxes show organisation factors that positively influence parental adaptation. Dashed lines indicating a negative influence on adaptation.

For parents the formal diagnosis is not the beginning of their journeys. Prior to parents receiving a diagnosis for their child, they must go through the pre-diagnosis stage which includes a number of different challenges and issues (see Table 1). These included parents beginning to notice behavioural signs of the disorder such as delayed developmental milestones and language development. This period is also characterised by confusion and uncertainty of behaviour which can lead to parents over-analysing their child's behaviour and seeking often misinformed answers. This was compounded by parents seeking help online.

Parents also mentioned that during this period they had feelings of self-blame that the child's behaviour was of their doing, including feelings of their

parenting being judged and suggestions that it was their parenting that needed to change. Parents also experienced frustration over delays before they finally receive an appropriate diagnosis as during this time they may be given false reassurances from the GP that their child's behaviour is not abnormal. During pre-diagnosis participants also identified organisational factors that assisted with these challenges (see Figure 2).

Table 1.

*Selected Quotes for Issues Faced by Parents during the Pre-Diagnosis Stage*

Noticing Behavioural Differences	"His milestones were delayed um, but in retrospect he was kind of just his own person, so we kind of created a bit of a narrative to explain that to ourselves."
Feeling Judged	"...suggestions that our parenting needed to change and yeah maybe if we just smacked him. Which I laugh at now but goodness at the time you know I didn't know whether to cry or explode."
Over-Analysing Behaviour	"I found it really hard to enjoy him for who he was on some level because I was always analysing his behaviour."
Searching for Answers	"Oh confused, I googled everything, and I'd come up with the stupidest things and be like oh my god my son's got some big word..... Cause there's so many things an autistic child's got and you'd google two of them and it would come up with some other stupid answer."
Long Wait Period	"I was getting a bit frustrated that I wasn't getting a time or date for assessment."

**Organisational factors which influenced adaptation during the pre-diagnosis stage.** Parents mentioned a number of different resources that they were referred to through the organisation to assist with the pre-diagnosis stage. These included being referred to a social worker, online support and being referred to the

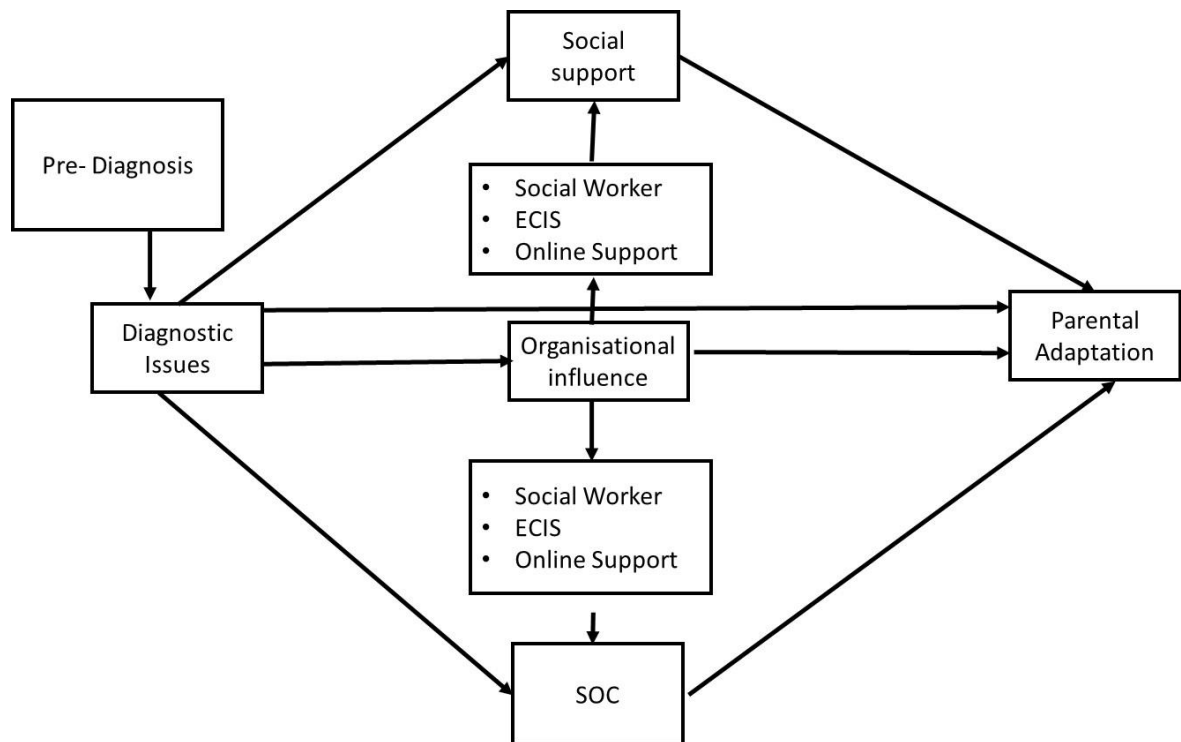
Early Childhood Intervention Service (ECIS). Examples of these resources are shown in Table 2. These resources assisted parents by influencing parent's SOC or social support as shown in Figure 3.

Table 2.

*Selected Quotes for Organisational Factors that Influence Adaptation during the Pre-Diagnosis Stage*

Online Support	“We could kind of chat about how you know, how we were coping with the whole process of assessment and diagnosis ..... a few people from that group started a Facebook group and that's been a lifeline for me in lots of ways, and I'm still friends with many of those people five years later.”
Social Worker	“[Social worker] was really helpful she suggested book and sites that we could get information from rather than me on the internet and the terrible stories that can be found.”
ECIS	<p>“Finding other mothers in the area basically dealing with the same thing. So being able to just talk with some of these other mothers.”</p> <p>“It gave me the opportunity to meet other mothers and get [child's name] sort of interacting with others.”</p>





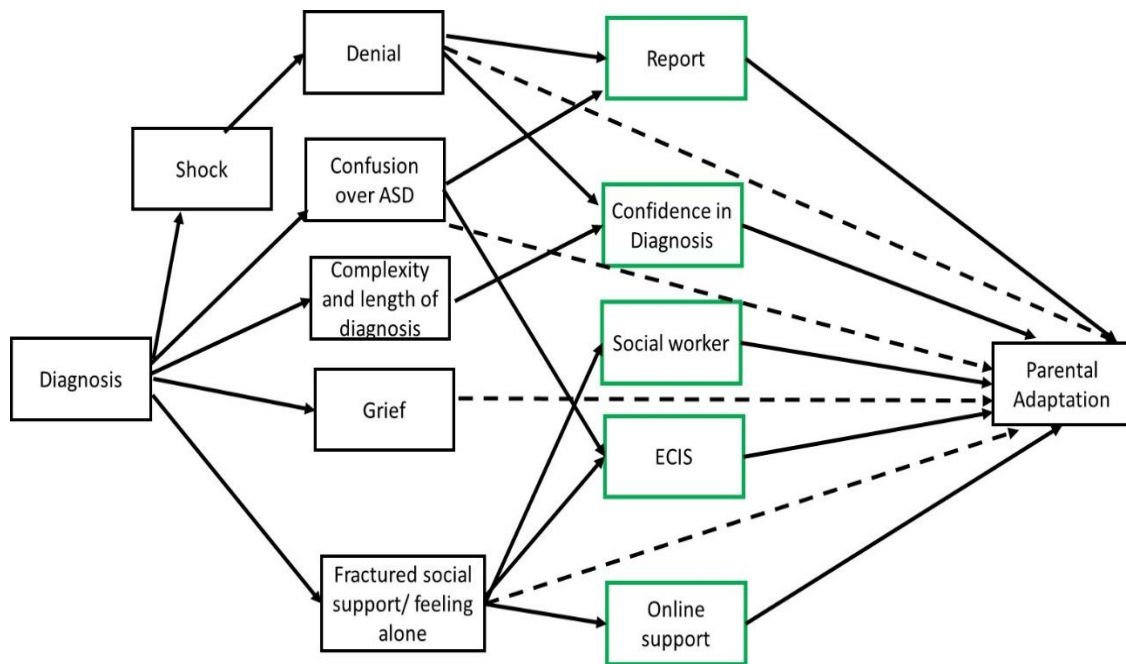
*Figure 3.* Model of the organisational factors during the pre- diagnosis stage that positively influence parental adaptation by influencing parent’s SOC and Social Support.

**Social worker.** One of the parents within the study was referred to a social worker during the stage awaiting a diagnosis and stated that this service was ‘invaluable’ to her experience. As shown in Figure 3, the social worker assisted parents by influencing social support and SOC. Social Support was provided by the social worker “checking up on the family” to make sure they were looking after themselves. The social worker influenced parent’s SOC by providing the family with a list of appropriate literature and reading for the parents which gave parent’s increased knowledge of ASD. The Social worker also made the mother feel as though they were not in limbo as they had someone they could have direct communication with to explain the process, which assisted in making the waiting period easier.

***Online support.*** Another mother stated that St Giles had recommended her onto an online forum ‘The Raising Children’s Network’. This forum offered an online environment within which parents could chat with and ask questions to other parents who were going through the diagnostic process or have had a child diagnosed with autism. Online support also influenced parent’s SOC and social support. Social Support was provided by allowing parents to connect with other parents that were going through the same thing and allowed the individuals to discuss the process and how they were coping, which one mother stated was a ‘lifeline’ during this period. Parent’s SOC was influenced by the site providing ‘trusted and reliable’ information to parents.

***Early Childhood Intervention Service.*** All of the mothers interviewed were referred to Early Childhood Intervention Service (ECIS) during the waiting period. The ECIS was a program for children with disabilities or developmental delays, with the purpose of providing families with advice that addresses their needs as well as giving them access to therapy which can benefit their child. ECIS influenced parent’s social support as well as SOC. ECIS allowed parents to connect with other mothers who were also going through the same stage which increased parent’s social support, but it also allowed parents to learn strategies to support their child and encourage their children to engage in social interactions which increased SOC.

## Diagnosis



*Figure 4.* Model of factors influencing parental adaptation during the diagnosis stage. Green boxes show organisational factors that positively influence parental adaptation. Dashed lines indicate a negative influence on adaptation.

The diagnosis stage refers to the period of going through the assessment and receiving a diagnosis. Though parents primarily described this period in a positive way, there were also a number of issues that parents faced (see Table 3). The diagnosis stage was said to be long and at some stages quite difficult; one example is the parent interview as this is an intense procedure. During the diagnosis period parents also faced a number of personal issues such as family conflict and fractured social support systems as well as relationship strain and feeling alone. There were, however, organisational factors that assisted parents during this stage (see Figure 4).

When parents receive the diagnosis, they can experience mixed emotions including relief, shock, denial and grief. Some parents also mentioned feeling relieved that their concerns were confirmed and grief as they anticipated the future for themselves and their child. It was also mentioned by one mother that upon receiving the diagnosis she was confused over what the diagnosis actually meant.

Table 3.

*Selected Quotes for Issues Faced by Parents during the Diagnosis Stage*

Length of Diagnostic Process	“It was at least two months I think, so quite long because he was fairly complex and they wanted to see him in different contexts and kind of do a really thorough assessment.”
Complexity of Diagnostic Process	“The Autistic diagnostic interview, I found that surprisingly difficult, in some ways to think, to be able to come up with specific examples of behaviours like it’s a quite intensive interview in terms of content to get through.”
Family Conflict/ Fractured Social Support	“Our extended family, and not all of them were that supportive of us seeking a diagnosis um so our usual support network was a bit fractured... so we were kind of askew from our usual support network.”
Relationship Strain	“So things like our marriage was under strain.”
Feeling Alone	“Nobody was there.”
Grief	“I wasn’t grieving for my son. I was grieving for me. I was grieving for the loss of MY expectations and MY dreams for my son. My son is quite possibly the happiest child on the planet (online).”
Shock	“Yeah well even though we were really prepared in some respect we still were shocked.”
Denial	“I was still in a bit of denial that there was something else.”
Confusion over ASD	“I didn’t know what autism was ...I was a bit shocked and I thought autism was the behaviour of the naughty kids, you know that’s what I thought it was and I thought if that’s what they diagnosed him with that’s what he has.”

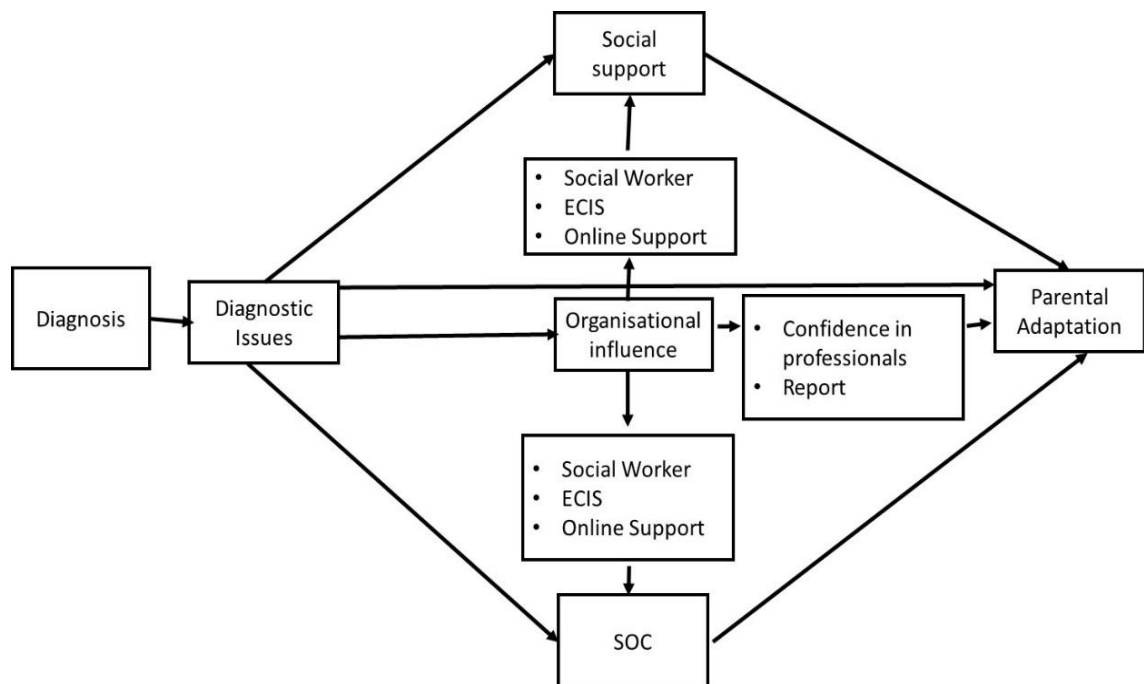
**Organisational factors which influence adaptation during the diagnosis stage.** Parents mentioned a number of different organisational factors and resources they were referred to through the organisation to assist throughout the diagnosis stage. Factors included having confidence in the professionals and the diagnosis,

having relationships with professionals and being provided with a comprehensive report. Resources included being referred to the ECIS, having a social worker and having the online support. Examples of these resources are shown in Table 4. These factors assisted parents by influencing parent's SOC, social support and increasing acceptance of the diagnosis (see Figure 5).

Table 4.

*Selected Quotes for Organisational Factors that Influenced Parental Adaptation**during the Diagnosis Stage*

Confidence in Professionals and Diagnosis	<p>“I wouldn’t feel comfortable like having a registrar from the hospital doing that assessment. Um I’d want to know that the person doing the assessment has had specific training with autism spectrum disorders and developmental delays, um you know, and also cause autism is not a medical diagnosis at the end of the day it’s a behavioural one so you need to have people who are trained in that field.”</p> <p>“I was happy with the amount of time ... I was really happy that it took quite a you know spent so much time getting to know him and him in different contexts as well.”</p>
ECIS	<p>“It gave me the opportunity to meet other mothers and get [child’s name] sort of interacting with others.”</p>
Online Support	<p>“The raising children’s network allowed me to link in with other parents that had children with autism. And it’s also a source of really good information about autism and about therapy and interventions, it’s like a reliable source. I felt quite confident getting information from that source I suppose.”</p>
Social Worker	<p>“She was amazing even though the process was a long one, and even through the actual assessment process there were lots of different tests and observations she was just there and explained the whole process and was someone who every couple of weeks would give us a call and see how we were going, and just explained the whole process. So that to us was really just invaluable.”</p>
Report	<p>“So we had this source of information that we could keep coming back to. Everything was explained including the actual processes and arriving at the decision, and um the certain aspects of the diagnosis.”</p>



*Figure 5.* Model of organisational factors during the diagnosis stage that positively influence parental adaptation by influencing parent's SOC, social support and acceptance of the diagnosis.

***Confidence in professionals and diagnosis.*** Parents reported that they had high confidence in the allied health team conducting the ASD assessment. Having confidence leads to increased assurance and acceptance in the final diagnosis. Although the assessments was time consuming, parents felt comfortable with the time it took to conduct the assessment as they felt that the DAT team were examining their child in all possible contexts to get an accurate representation.

***Report.*** The report gave parents a source which they could continually come back to, to explain the diagnostic process and why that diagnosis had been prescribed. One mother said that having the report allowed her husband to accept the diagnosis; though he wasn't involved in the whole process, having the report allowed him to have an explanation of the diagnosis and how this diagnosis came about.



***Online Support.*** The online support again provided parents with increased social support and SOC. Providing parents with alternate social support was particularly important during this stage as it was mentioned in a number of interviews that parents felt alone or askew from their usual support network due to reasons such as family not being supportive of the diagnosis. Having access to an online source allowed parents to have constant access to support. Due to the anonymity of the online environment parents also did not feel judgment.

***ECIS.*** ECIS again benefitted parents by influencing parent's social support and SOC.

***Social Worker.*** As in the pre-diagnosis stage, the social worker provided parents with social support and increased SOC. During the diagnosis stage social workers assisted by explaining the diagnostic process to parents which allowed the parents to feel more knowledgeable about the process.

***Positive Implications of an ASD Diagnosis.*** Upon receiving a diagnosis parents also mentioned a number of positive outcomes (see Table 5). Parents mentioned that they felt relieved that their concerns had been confirmed and it had not been something they had done. Providing parents with a label enabled them to explain their child's behaviour to themselves, their child and to others. It also allowed them access to certain resources such as funding and therapies.

Table 5.

*Selected Quotes for Positive Implications of Receiving a Diagnosis of ASD for Parents during the Diagnosis Stage*

Relief	“It was a relief, confirmation that yes he does have autism. And I was thinking that maybe I’d done something wrong earlier on by not encouraging him more or interacting with him more. But yeah it explains why he is the way he is.”
Having Answers	“He was finally diagnosed with something instead of being pushed away, you know I hated that. Yeah so just the full diagnosis so then I could actually help him.”
Access to Therapy	“It’s enabled us to access the ABA therapy that we may have struggled to afford if we hadn’t had the autism funding.”
Accept Child’s Differences	“I definitely felt it helped me to enjoy him. And it improved my response and gave me a better understanding and took away the doubt and need to constantly scrutinise him and everything he did. It was quite freeing.”
Explaining Differences to Child	“I think ultimately and especially as he is getting older that the diagnosis helps him to understand himself, which is probably the most important thing for me. That he grows up knowing he has a different way of perceiving the world to peers but that’s not a wrong thing, you know it’s just the way his brain is and there’s some real positives to being autistic.”

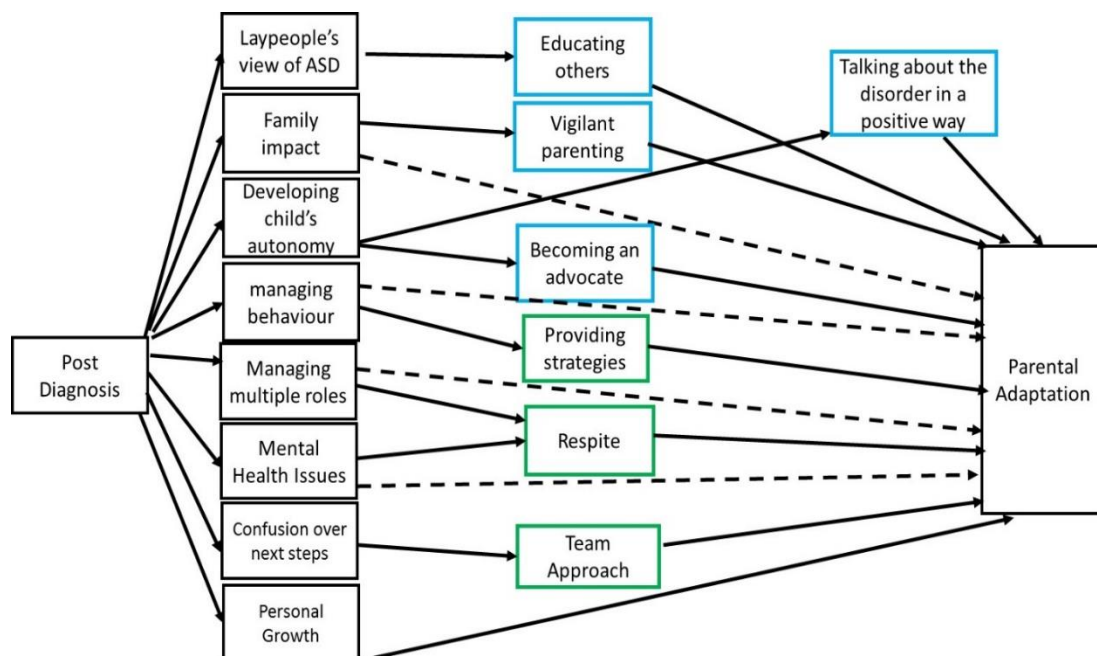
***Confusion over ASD diagnosis.*** Though the overall satisfaction with the diagnosis was positive, one mother felt that the information given at the time of the diagnosis was not sufficient and that she wanted more tailored and practical advice about how to parent a child with ASD.

*“Just someone to sit down with you and tell you about autism, like how we’re sitting now face to face explain it yeah instead of me going home googling and googling the wrong thing as well, somebody who is an expert in autism to sit there and explain the whole shebang, and then somebody to come into your home and teach you other*

*things as well, like how to live with an autistic child day to day, cause some things were tricky that I had to work out myself."*

Although this could indicate issues with the information given, it also may also indicate that parents do not have the capabilities to utilise or understand the information given which may suggest the diagnosis needs to be given in a way tailored to the individual's needs.

### Post- Diagnosis



*Figure 6.* Model of factors that influence parental adaptation during the post diagnosis stage. Green boxes indicate organisation factors. Blue boxes indicate personal strategies that positively influence parental adaptation. Dashed lines indicating a negative influence on adaptation.

The post diagnosis stage refers to the period after diagnosis. As this stage, parents are trying to accommodate this new information into their lives. Initially after diagnosis, one mother mentioned that she felt a bit unsure of what the next step would be in terms of assisting her child and implementing the diagnosis into her life. Parents also felt a number of personal struggles whilst trying to adjust to normal life, including trying to moderate the impact of the diagnosis and their child's behaviours on their other children. Parents also had to deal with stigma, including their extended families perception of autism. Whilst these issues were occurring parents were also transitioning into therapy and working to facilitate intervention and behavioural management of their child. These issues are shown in Table 6. In this stage organisational resources that positively influence parental adaptation were also identified (see Figure 6).

Table 6

*Selected Quotes for Issues Faced by Parents during the Post-Diagnosis Stage*

Managing Multiple Roles	“The big challenge for me is finding the time to fit in all of the help that he needs, plus time for us as a family, for his sibling, for our marriage.” (Online source)
Mental Health Issues	“I got depression... four and a half years ago I got depression so it would have been 6 months into his diagnosis... Uh I got depression but I think a lot contributed to it. I got a divorce, my child got diagnosed with autism and I did feel alone... I swear the autism diagnosis did affect me.”
Confusion over where to Next	“Because there was so much inertia there throughout the actual diagnosis and all the different tests and assessments and that sort of stuff. When we were actually given the diagnostic report you kind of go into a ‘oh ok what next’ kind of thing.”
Uncertainty over Future	“You get this idea of what your child is going to be like, and then the unknown is sort of there too so there was this okay we had imagined these beautiful milestones....When you are actually faced with the possibility that the child possibly has a disability or a developmental difference you are kind of stuck with the unknown.”
Impact on Family	“With our own parenting we have to be very careful our other children aren’t enduring too much stress or having to accommodate more than you know they’re able.”
Laypeople’s View of ASD	“She thought the worse as well she thought somebody that would grow up and still live with mommy and daddy and still be special.”
Developing Autonomy for Child	“His special interest seem to whack and wain he does move on from them....When he was obsessed with tropical fruit, we thought for a while that he might end up doing farming (laughs) so we took him out to the berry farm and um helped him experience those things.”
Future Thinking	“We might have someone living with us as a young adult as well, a lot longer than the others. Um so yeah we have to plan for the future in a pragmatic way. Yeah so like most people with nine year olds aren’t planning for having a twenty something still or well a thirty year old living at home with them but still that’s a distinct possibility.”

While parents had to deal with a number of difficult issues post-diagnosis, they also stated that there had been some positives of having a child with ASD as shown in Table 7. The mothers talked about having changed outlooks, becoming more empathetic and compassionate as well as less judgemental. They also mentioned joy and not taking things for granted.

Table 7.

*Selected Quotes of Positive Implications of having a Child Diagnosed with ASD*

Personal Growth	“We’re so much more compassionate people, so much more empathic to other people. I think when you’re making sure your child’s polite and that kind of stuff you can become quite judgemental. And so you know now the reflex for us now isn’t gee I wish that mum could teach that child to eat with his mouth closed or whatever (laughs) it’s like ok well there might be something more going on”
Joy	“In some ways it’s brought us more joy than you know, we could imagine. Um you just don’t take things for granted um and when a child has had a happy day we’re in that moment with him completely because we’re just so thankful that he’s having a positive experience.”

**Organisational factors which influence adaptation during the post**

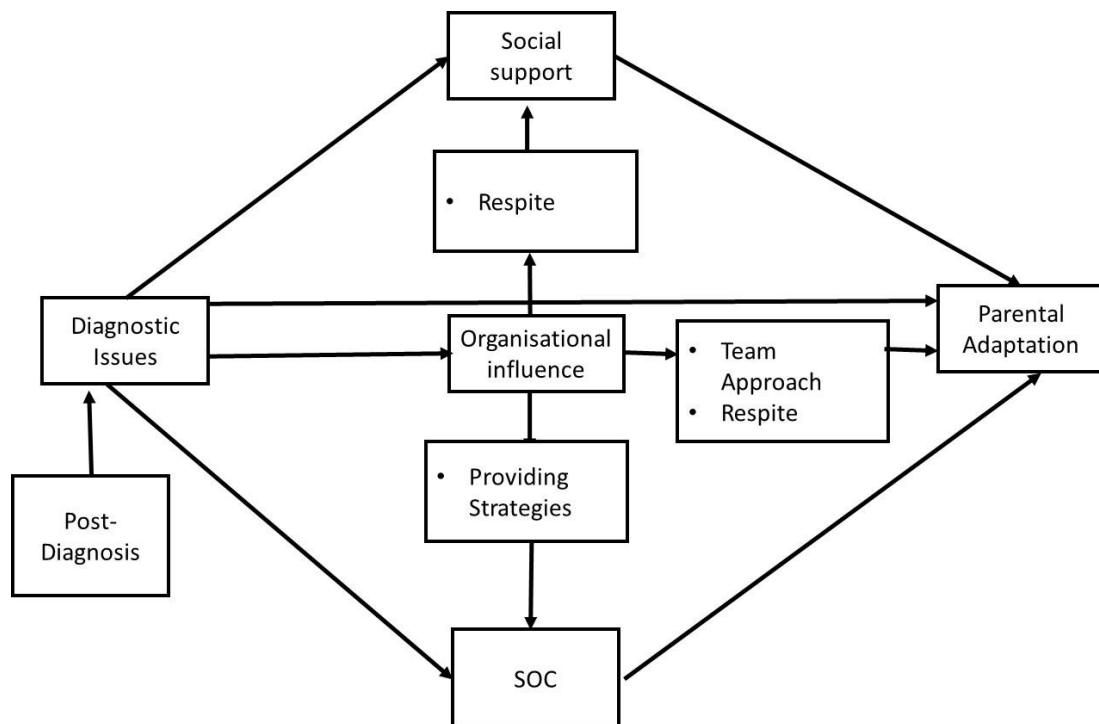
**diagnosis stage.** Throughout this period parents mentioned a number of different resources that they were referred to or provided through the organisation. These included being referred to respite services, having the team approach and being provided with strategies to assist their child. Examples of these resources and factors

are shown in Table 8. These resources assisted parents by influencing parent's SOC, social support and accomoation of the diagnosis as shown in Figure 7.

Table 8.

*Selected Quotes of Organisation Factors that Influenced Adaptation during the Post Diagnosis stage*

Respite	"I'm looking into getting some domestic help as well so I can have more time with [child's name] helping with like occupational therapy at home, rather than house work. I do feel guilt I do spend too much time doing housework than time with him."
Team Approach	"Having the team diagnosis as well as obviously having all those other professionals involved meant that as soon as we did get a diagnosis we were able to commence therapy. The therapists knew exactly what they were dealing with."
Providing Strategies	"Yeah they gave me lots of recommendations of things that might be helpful for [child's name]...they gave me some good information about separation anxiety, and how to manage that, um and you know options for therapy."



*Figure 7.* Model of the organisational factors during the post-diagnosis stage that positively influence parental adaptation by influencing parent's SOC, social support and accommodation of the diagnosis.

**Respite.** Parents highlighted the benefit of respite or having a consistent babysitter as it allowed them to spend some time 'away from autism'. Initially this could be simply taking time out to walk around the block. This was suggested to facilitate the mother's mental health as it allowed her to spend quality time with her partner and work on their relationship. One mother also talked about getting help for domestic duties so that she could spend some more time on therapy with their child, as managing multiple roles could be a source of guilt for her.

**Team Approach.** Having the team consisting of multiple professionals was beneficial as it allowed for multiple perspectives and greater accuracy during the



diagnosis. This also allowed for the transition into therapy to be easier as (if the parents chose to access therapy through St Giles) the therapist was already aware of their child's condition.

***Providing Strategies.*** Once the diagnosis was given, the DAT team gave additional information to parents. This included a list of contacts that they could reach to gain support as well as information on strategies that may be useful for their child. This provided parents with concrete steps they could take to influence their child's development, therefore empowering parents.

**Personal factors which influence adaptation through the post-diagnosis stage.** Within this stage parents also mentioned a number of personal strategies that they had implemented or used to assist the adjustment to having a child with ASD and facilitate positive adaptation. Examples of these are demonstrated in Table 9.

***Talking about ASD Disorder in a Positive Way.*** By discussing the disorder in a positive way, particularly with family and the child with ASD, it allowed the disorder to not become a burden in the family but instead a point of difference which should be celebrated. One mother mentioned that her child talked about ASD as his 'super power'. By talking about the disorder in a positive way it allowed her child to have a more positive outlook on himself.

***Becoming an Advocate.*** One mother mentioned that quickly after they had received a diagnosis she became aware of current legislation and rules regarding having a child with a disability. Having this knowledge empowered her as it allowed her to be sure of what was and what was not appropriate, such as use of disabled toilets. Parents described this as particularly difficult with children with autism as the child does not have a physical disability.

***Educating Others.*** Talking about the disorder within the family and giving them an understanding of autism allowed for family to better understand the situation which therefore increased access to family as social support. One mother mentioned that originally when she told her parents about her child being diagnosed with ASD they thought of those who were institutionalized; she then helped educate them by watching movies and documentaries together.

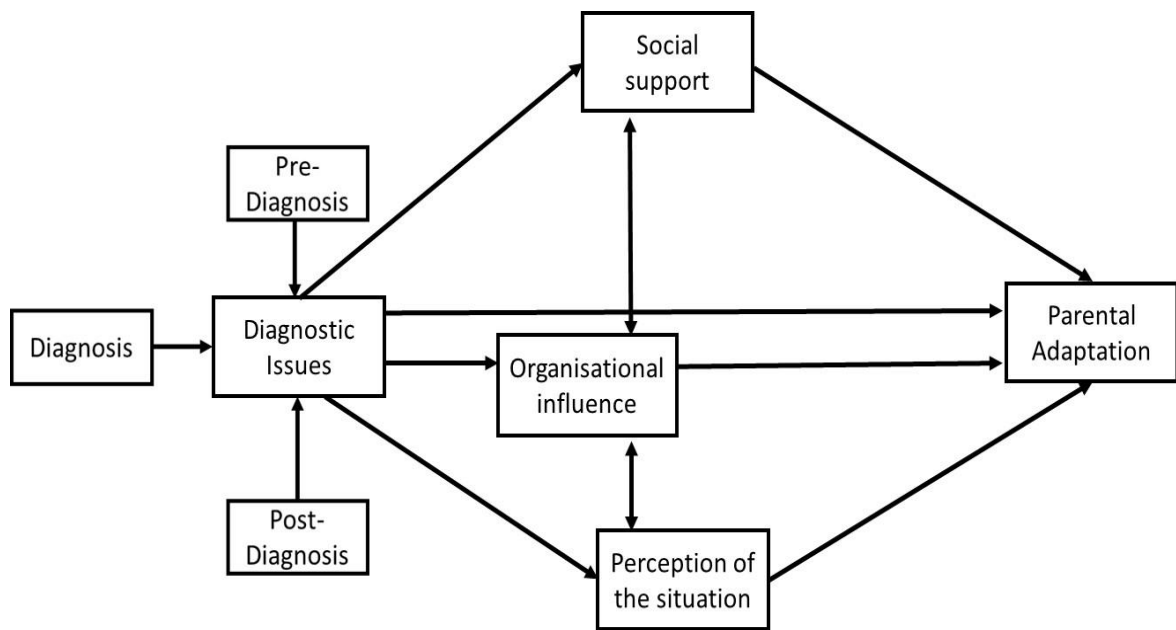
***Vigilant Parenting.*** Parents highlighted the importance of having to become a ‘super parent’ and becoming completely focused on every aspect of their child’s world. It was mentioned by a number of parents that they had to develop a sense of increased vigilance as well as organisation. For example, parents described taking extra resources in case of particular behaviours when leaving the house. They would also plan for transitional periods in life, such as their child changing classes, by going into school in the holidays and meeting teachers. Parents also talked about the importance of managing the ASD so that her other children did not have to ‘walk on egg shell’ but instead could have a normal childhood. For a summary of these adaptive strategies see Table 9.

Table 9.

*Selected Quotes for Personal Adaptive Strategies throughout the Post Diagnosis**stage*

Talking about Disorder in a Positive Way	“He’s talked about autism as his super sense so that he’s got these super sense because he has autism like being able to hear things really well, being really strong and having a super smell, like he can smell anything. So it’s great cause he’s growing up with a really um positive view of himself and hopefully realising that being autistic is a good thing and it makes him who he is and his brother as well. To me in terms of autism acceptance in his self, that’s really been key.”
Becoming an Advocate	“Yeah we’ve learnt to advocate for ourselves quite a bit yeah you end up kind of suddenly knowing a whole heaps of policy and legislation and what’s okay and what’s not okay. Toilets in public places and that sort of thing (laughs) so you’re able to fight for yourself.”
Family Discussion/ Educating Others	<p>“I try talk about it as [child’s name] has, these are things he finds difficult to do but there’s some really cool things he’s really good at, so we’ll talk about that then we’ll talk about how we all have things we’re good at and not so good at.”</p> <p>“I had to get my mother and father to watch documentaries and you know movies.”</p>
Vigilant Parenting	“You kind of become really vigilant I guess um yeah so we have to be really prepared we take headphones when we go places, we take little toys, we take spare medication (laughs), we have the visual um to prepare him for changes. Yeah um if we’re going somewhere new we’re often on google maps and having a look at the street scape and the picture of some of the buildings.”

### Overall Adaptation



*Figure 8.* Overall model for factors that influence parental adaptation during the full ASD diagnostic process

The results from the thematic analysis demonstrate how parents adapt to issues at each stage within the diagnostic process by utilising the resources of social support and SOC. The results also show that these resources are influenced by organisational factors and resources provided throughout the diagnostic process, which can therefore positively facilitate adaptation. Social support for parents can be influenced by resources such as a social worker, online support, ECIS and respite. These resources allow parents to connect with other parents who are going through the same thing or provide a constant source of support through access to the social worker. Being referred to a social worker, ECIS, online support, report, confidence in diagnosis and being provided with strategies allows parents to develop knowledge and strategies (and consequently their SOC) which can influence their ability and perception in raising a child with ASD.

## **Discussion**

### **Overview of the Study**

The purpose of this qualitative study was to address a gap in the literature by developing a multidimensional model to explain the influence of the diagnostic process on parents overall adaptation. This evaluation of parent's experiences and perceptions of the ASD diagnostic process through the St Giles multi-disciplinary team provides a useful understanding into the stages, processes and issues of receiving a diagnosis of ASD for a child. This model provides important insight into the way that factors within the diagnostic process can be used to influence parent's social support and sense of coherence (SOC) to facilitate positive parental adaptation to issues. These results, however, highlighted that there are a number of issues that may complicate parental adaptation, as well as suggestions for potential improvements to service delivery.

Previous research within this area has generally looked at factors such as social support or individuals SOC as separate characteristics. Through this investigation, however, it became apparent that due to the complexity of the diagnostic process and in order to fully understand parental adaptation research needs to be done by integrating multiple factors. It is also apparent that in order to safeguard a parent's mental health, support and guidance needs to be provided early in the process to facilitate positive adaptation therefore emphasising that it is beneficial to see how the diagnostic process can be tailored to parent's needs.

## Interpretations of the Findings

Using thematic analysis, issues that parents faced during the diagnostic process were identified as well as factors that may assist parents in positive adaptation. Results suggest that parents adapt to the issues within the diagnostic process by utilising their social support and SOC which can be influenced by organisational factors. This model was an extension of McCubbins and Patterson's (1983) Double ABCX model of adaptation and adjustment, which had previously not been utilised to evaluate how these factors can be facilitated by the diagnostic process.

*Issues parents faced throughout the diagnostic process.* Throughout this study a number of issues parents faced throughout the diagnostic process were highlighted, consistent with previous literature. During the pre-diagnosis stage, parents had concerns over their child's behaviour and feelings of self-blame (Midence & O'Neill, 1999), frustration over long wait times (Mansell & Morris, 2004; Howlin & Moore, 1997; Smith et al., 1994), and dealing with social stigma (Mansell & Morris, 2004; Gray, 2002). During the diagnosis stage, parents had concerns over the complexity and length of the diagnostic process (Braiden et al., 2015).

During the post diagnosis stage, parents also faced a number of issues consistent with the literature. Parents felt feelings of shock (Siegel, 1997), Greif (Avdi, Griffin & Brough, 2000; Midence & O'Neill, 1999) and denial after the diagnosis was given. Parents also reported concerns over their child's future and dealing with laypeople's view of ASD (Mansell & Morris, 2004). Consistent with

the literature, however, was the joy and personal growth that can come from raising a child with ASD (Stainton & Besser, 1998).

***Social support.*** The importance of social support was a strong theme of influencing parental adaptation within this study. Parents mentioned Early Childhood Intervention Services (ECIS), being referred to a social worker and the online forum as sources of social support. Within this study it was found that a number of parents felt alone and askew from their normal support networks due to reasons such as their family not being supportive of the diagnosis. This highlights the importance of providing parents with formal forms of social support during the diagnostic process and is consistent with previous literature suggesting social support can play a protective role in reducing the impact of parental stress (Bristol & Schopler, 1984; Dyson, 1997).

***Sense of coherence.*** The importance of parent's perceptions in their ability to deal with the situation was also highly important. SOC was influenced by resources such as ECIS, being referred a social worker, online support and being provided with strategies. These resources influenced SOC by increasing parent's knowledge and their feelings of capability. Antonowsky (1987) suggests that SOC was the ability to view one's life as more predictable and manageable, but also that this mindset could influence a more positive and mobilising coping style. This was also found by Pozo and colleagues (2006) who found SOC to be a mediator between symptom severity of the child with autism and parental stress.

***Early Childhood Intervention Services.*** ECIS provided parents the opportunity to connect with other parents and carers who were going through the same situation therefore increasing their social network and support. The

effectiveness of early intervention programs on children with ASD has been noted (Warren, McPheeters, Sathe, Foss-Feig, Glasser & Veenstra-VanderWeele, 2011), consistent with our literature these programs have also been found to be effective in also benefitting parents (Tonge, Brereton, Kiomall, MacKinnon, King, & Rinehart, 2005). Benefits can include reducing stress that arises from parenting a child with ASD and increasing parent's self-efficacy (Keen, Couzens, Muspratt, & Rodgers, 2010). These benefits can stem from parents increasing their SOC as providing parents with concrete strategies for their child, as ECIS does, increases their sense of control over the situation (Pozo et al., 2011).

***Online Support.*** For parents, online support provided sources of knowledge that could influence their SOC as well as their social support. Research has increasingly investigated the use of social forums and identified the benefits in using these to connect people with sources of social support (Grieve, Indian, Witteveen, Tolan & Marrington, 2013; Wright, 2000). Due to the high level of anxiety and uncertainty individuals can have when their child is diagnosed with ASD, parents may be highly motivated to seek social comparison with others who are going through the same thing; online sources can be preferable due to their anonymity (Bargh & McKenna, 2004). Due to the stigmatization of autism parents tended to disengage with social activities therefore having an online network allowed them to connect without increased stress. A study by Huws, Jones and Ingledew (2001) looked at how parents obtained support through the use of an email group. The study found that that this group provided a number of different resources to parents including encouragement, emotional and esteem support, and sharing of experiences. Unlike other support groups, online support is also beneficial as there are no time or



accessibility constraints, which may be important due to the increased time requirements of having a child with ASD.

***Social Worker.*** Being referred a social worker was found to be a source of social support but also influenced parent's SOC by providing them with knowledge. The social worker suggested relevant and reliable readings for the family. Having knowledge is important in adaptation, as research by Luthra and Perry (2011) found knowledge to be a predictor of positive parental outcomes. Though this knowledge may not directly influence how parents adapt, the research shows that it can influence parents by increasing their perceptions of how much they know and their ability to cope with the situation. Having information empowers parents when they have the resources to use the knowledge, which in turn influences their SOC.

***Confidence in diagnosis.*** Having confidence in the diagnosis was important for parents going through the diagnostic process. It was found that for some parents the assessment process was considered challenging and intense. This, however, was not a major issue for parents as they felt confidence in the process being undertaken, with some stating that they believed that the team 'left no stone unturned'. Confidence in the diagnosis was influenced by a number of diagnostic factors including having a team involved in the process. This team diagnosis made parents feel that they were getting multiple perspectives of their child, and that the allied health professional were triangulating their data therefore leading to a more accurate diagnosis. The diagnostic report was another factor that influenced parent's acceptance of the diagnosis as it offered parents an explanation of how the child was diagnosed and what this meant, thus giving parents clarity.

By having confidence in the diagnosis parents were more able to accept the diagnosis and consequently progress in the process of adaptation. This finding was supported by earlier work from Watchel and Carter (2008) who found that when mothers had more acceptances and were more emotionally resolved they had better interactions with their child. Combined with this past literature, the current study highlights the importance of ensuring the mothers resolution regarding the diagnosis, and its potential influence on overall adaptation.

### **Implications for Service Delivery**

The process of adaptation to a diagnosis is complex, with a great number of factors influencing this process. The results of this study indicate that these factors need to be looked at using a multi-dimensional approach in order to gain a comprehensive outlook on the issues that affect parents. It is important that the process used by services such as St Giles need to be informed by an understanding of the complex interaction between personal and social context factors.

Previous research has shown that there are four stages of a diagnosis; pre-diagnosis, diagnosis, post diagnosis and acceptance and adaptation (Howlin & Moore, 1997). This study determines the issues that arise at each stage of the diagnostic process and identifies the type of support that parents need for each stage. For example, it is essential that formal support be provided throughout the diagnostic process as it became clear that parents could not always rely on their usual support network during this time, however the importance of social support during adaptation is clear. This suggests that service deliverers need to be conscious of providing parents with support that addresses their needs during specific times.

This study also identifies the importance of resources that promote positive adaptation and the need to ensure all mothers have access to these. While many of the resources referred to parents were described as beneficial, not all parents interviewed had access to these. For example, only one mother who was interviewed had the opportunity to access a social worker, despite the fact that she said this service was ‘invaluable’ to her experience as the social worker provided support, information and empowerment. This may suggest that this service of referring parents to a social worker, needs to be investigated, and that service delivers need to consider implementing such resource to all parents going through the diagnostic process.

It also became apparent that though there were a number of different community and organisational-based resources that parents could access, they may not have been aware of these. Parents were given a comprehensive list of local support after they received the diagnosis, however it also may be recommended that after the diagnosis is given, the DAT team discuss the different options of support with parents in order to assist parental understanding.

The research also shows that the diagnostic process may need to be tailored to meet the individual needs of the parent. Though multiple resources were provided to parents it also depends on the parent’s ability to utilise these services. Although resources can be provided, if a parent does not have the desire or capabilities to access these, then resources cannot facilitate parental adaptation. This result may suggest that after the diagnosis has been given, parents should be followed up by someone in the DAT team to answer any questions they may have. Empowerment of parents would also be assisted by having a social worker assigned so that at any time during the process parents can call and ask questions.

## **Limitations of the Current Study**

Whilst thematic analysis can be used to identify adaptive factors which facilitated positive adaptation during the ASD diagnostic process, the relative importance of each factor is unknown. By understanding this hierarchical nature, a more comprehensive understanding of factors and their relationships to one another and mother's adaptive capacity could be determined. Content analysis could have been used to determine the relative importance of each theme or category thus overcoming this limitation. Content analysis, however, does require greater sample sizes than obtained in this study therefore indicating that this would be a possible future direction when using larger sample sizes.

The major limitation for this study was the small sample size. Qualitative research aims to describe the range of experiences in a population and capture variability in participant's responses. Due to the small sample size it is highly likely that the views captured may not be fully representative of the experiences of all mothers who have gone through the diagnostic process. It is possible that mothers with fewer comments to make in regards to the diagnostic process were less likely to participate in the study. This issue further limited generalisations of the current study.

Given the small sample size it was difficult to determine saturation. Some themes emerged repeatedly across interviews and appeared to be saturated (i.e. no new information was gained from later interviews). Other themes, however, were only identified by one or two participants and would require further data collection to determine saturation. While all possible steps were taken to facilitate participation

given the time frame, it was not possible to achieve the sample size required to achieve saturation of all themes.

The initial methodology of the current study included interviewing three groups of participants, one group at each stage of the diagnostic process (pre-diagnosis, diagnosis and post-diagnosis). Due to the limited response rate, use of only one group was viable. Regardless, the study was still able to investigate the issues parents faced during each of these stages as all had reached the final stage of the diagnostic process. This, however, raised a further issues as most participants had received the diagnosis at least two years prior to the study, thus potentially introducing issues can arise from reflective thinking including inaccurate recall and hindsight bias (Jasper, 2005). These issues are further compounded by varying amounts of time between the time of diagnosis and the current study, ranging from just under six months ago to almost 5 years ago.

In thematic analysis research, initial interviews are exploratory in nature. As themes emerged and comparisons are made between them, further questions which deepened the understanding of categories and their properties became necessary. With a greater number of participants, additional questions generated in coding of cases would have been added to subsequent interviews. This could also be an issue for future research.

### **Future Research**

Future research would be beneficial to empirically validate the results. This could be done through the development of a questionnaire to assess the many factors that influence parental adaptation during an ASD diagnosis. Such a tool could have

considerable utility for validating the proposed model and as well as in the assessment of parental adaptation.

Through this study, the importance of this area of research became apparent therefore it would also be beneficial to do a longitudinal study within this area. This would allow researchers to evaluate how facilitating positive parental adaptation during the diagnostic process can improve long term adaptation and improve the service delivery for parents.

## **Conclusion**

The current study has demonstrated the issues that mothers face during the diagnostic process, as well as factors which influence mother's ability to adapt positively to a diagnosis. As a result of thematic analysis, a model of parental adaptation during the diagnostic process of ASD was developed. This model aims to extend the current body of research beyond limiting parent's adaptation to post diagnosis but incorporating factors and resources that can assist this process throughout the initial stages. The study suggests that due to the complexity of an ASD diagnosis it is important to understand the factors that influence adaptation together, considering how they interact. While further research is needed, the current study suggests that all of these factors will be important in developing successful interventions for parents in order to facilitate positive adaptation. However, owing to the small sample size these conclusion must remain tentative until a more comprehensive study is undertaken.

## References

- Ahern, K. (2000). Something is wrong with my child: A phenomenological account of a search for a diagnosis. *Early Education and Development, 11*, 187- 201. DOI: 10.1207/s15566935eed1102\_4.
- American Academy of Paediatrics. (2001). Technical report: The paediatrician's role in the diagnosis and management of autistic spectrum disorders in children. *Paediatrics, 107*, 1-18. DOI: 10.1542/peds.107.5.1221.
- American Psychiatric Association. (2013). *Diagnostic and Statistical manual of mental disorder* (5<sup>th</sup> ed.). Arlington, VA: American Psychiatric Publishing.
- Antonovsky, A., & Sagy, S. (1986). The development of a sense of coherence and its impact on responses to stress situations. *Journal of Social Psychology, 126*, 213- 225, ISSN: 1099-0992.
- Antonovsky, A., & Sagy, S. (1986). The development of a sense of coherence and its impact on responses to stress situations. *Journal of Social Psychology, 126*, 213- 225, ISSN: 1099-0992.
- Avdi, E., Griffin, C. & Brough, S. (2000). Parents' Constructions of the "Problem" during the assessment and diagnosis of their child for an Autistic Spectrum disorder. *Journal of Health Psychology, 5*, 241-254. doi: 10.1177/135910530000500214.
- Banach, M., Iudice, J., Conway, L. & Couse, L. J. (2010). Family support and empowerment: Post autism diagnosis support groups for parents. *Social Work with Groups, 33*, 69-83. DOI: 10.1080/016095109034373383.

- Barbaro, J. & Dissanayake, C. (2009). Autism spectrum disorders in infancy and toddlerhood: A review of the evidence on early signs, early identification, and early diagnosis. *Journal of Developmental and Behavioural Paediatrics*, 30, 447-459. doi: 10.1097/DBP.0b013e3181ba0f9f.
- Bargh, J. A., & McKenna, K. Y. A. (2004). The internet and social life. *Annual Review of Psychology*. 55, 573-590. Doi: 10.1146/annurev.psych.55.090902.141922.
- Boyd, B. A. (2002). Examining the relationship between stress and lack of social support in mothers of children with autism. *Focus on Autism and Other Developmental Disabilities*, 17, 208- 207. DOI: 10.10.1177/10883576020170040301.
- Braiden, H. J., Brothwell, J., & Duffy, J. (2010). Parent's experience of the diagnostic process for autistic spectrum disorder. *The Child Care in Practice Group*, 16, 377- 389. DOI: 10.1080/13575279.2010.498415.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77- 101. DOI: 10.1191/1478088706qp063oa.
- Bristol, M. M. (1987). Mothers of children with autism or communication disorders: successful adaptation and the double ABCX model. *Journal of Autism and Developmental Disorders*, 17, 469- 486.
- Bristol, M. M. (1979). Maternal coping with autistic children: Adequacy of interpersonal support and effects of child's characteristics. *Unpublished doctoral dissertation*, University city of North Carolina, Chapel Hill.



- Bristol, M., & Schopler, E. (1993). Stress and coping in families of autistic adolescents, In: *Autism in adolescents and adults*, E. Schopler y G. B. Mesibov (Eds.), (251-276), Plenum Press, ISBN:1557661715, New York.
- Dabrowska, A., & Pisula, E. (2010). Parenting stress and coping styles in mother and fathers of pre-school children with Autism and Down syndrome. *Journal of Intellectual Disability Research*, 54, 266- 280. DOI: 10.1111/j.1365-2788.2010.0125.x.
- Duate, C. S., Bordin, I. A., Yazigi, L., & Mooney, J. (2005). Factors associated with stress in mothers of children with autism. *Autism*, 9, 416-427. doi: 10.1177/1362361305056081
- Dyson, L. I. (1997). Fathers and mothers of school-age children with developmental disabilities: Parental stress, family functioning and social support. *American Journal of mental Retardation*, 102, 267-279.
- Elliott, R., Fischer, C., & Rennie, D. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, 38, 215-229. DOI: 10.1348/0144665999162782.
- Falk, N. H., Norris, K., & Quinn, M. G. (2014). The Factors Predicting Stress, Anxiety and Depression in the Parents of Children with Autism. *Autism Development Disorder*, 44, 3185- 3203. doi: 10.1007/s10803-014-2189-4.
- Falkmer, T., Anderson, K., Falkmer, M., & Horlin, C. (2013). Diagnostic procedures in autism spectrum disorders: a systematic literature review. *Eur Child Adolesc Psychiatry*, 22, 239- 340. Doi: 10.1007/s00787-0130-0375-0.

- Goddard, J. A., Lehr, R., & Lapadat, J. C. (2000). Parents of Children with Disabilities: Telling a Different Story. *Canadian Journal of Counselling*, 34, 273-289.
- Gray, D. E. (2002). Everybody just freezes. Everybody is just embarrassed: Felt and enacted stigma among parents of children with high functioning autism. *Sociology of Health and Illness*, 24, 734–749. ISSN 0141-9889
- Gray, D. E., & Holden, W. J. (1992). Psychosocial well-being among the parents of children with autism. *Australian and New Zealand Journal of Developmental Disabilities*, 18, 83- 93. DOI: 10.1080/07263869200034841.
- Grieve, R., Indian, M., Witteveen, K., Tolan, G. A., & Marrington, J. (2013). Face-to-face of Facebook: Can social connectedness be derived online? *Computers in Human Behaviour*, 29, 604-609. Retrieved from: <http://dx.doi.org/10.1016/j.chb.2012.11.017>.
- Howlin, P., & Moore, A. (1997). Diagnosis in autism: a survey of over 1200 patients in the UK. *Autism*, 1, 135–162. Doi: 10.1177/1362361397012003.
- Huerta, M., & Lord, C. (2012). Diagnostic evaluation of Autism Spectrum Disorder. *Paediatr Clin North Am*, 59, 103- 111. DOI: 10.1016/j.pcl.2011.10.018.
- Huws, J. C., Jones, R. S. P., & Ingledew, D. K. (2001). Parents of Children with Autism using email group: A Grounded Theory Study. *Journal of Health Psychology*, 6, 569-584. Doi: 10.1177/135910530100600509.
- Jasper, M. A. (2005). Using reflective writing within research. *Journal of research in Nursing*, 10, 247-260. Doi: 10.1177/174498710501000303.

- Keen, D., Couzens, D., Muspratt, S., & Rodger, S. (2010). The effects of a parent-focused intervention for children with a recent diagnosis of autism spectrum disorder on parenting stress and competency. *Research in Autism Spectrum*, 4, 229- 241. Doi: 10.1016/j.rasd.2009.09.009.
- Landis, J. R., & Koch, G. G. (1977). The measurement of observer agreement for categorical data. *Biometric*, 33, 159-174. DOI: 10.2307/2529310.
- Luthra, N., & Perry, A. (2011). Knowledge as coping in parents of children with Autism. *Journal of Developmental Disabilities*, 17, 79-82.
- Mansell, W., & Morris, K. (2004). A survey of parents' reactions to the diagnosis of an autistics spectrum disorder by a local service. *Autism*, 8, 387- 407. DOI: 10.1177/136231304045213.
- McCubbin, H. I., & Patterson, J. M. (1983). The family stress process: the Double ABCX model of adjustment and adaptation, Social stress and the family: *Advances and developments in family stress theory and research*, H.I. McCubbin, M.B. Sussman y j. M. Patterson (Eds.), (7-73), The Haworth Press, ISBN: 0866561631, New York.
- Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis: An expanded source book* (2<sup>nd</sup> ed.). Newbury Park, CA: Sage.
- Midence, K., & O'Neill, M. (1999). The experience of parents in the diagnosis of autism: A pilot study, *Autism*, 3, 273-285.

- Moore, T. R. (2009). Adherence to behavioural and medical treatment recommendations by parents of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 39, 1173–1184. Doi: 10.1007/s10803-009-0729-0.
- Mulligan, J., MacCulloch, R., Good, B., & Nicholas, D. B. (2012). Transparency, hope and empowerment: A model of partnering with parents of a child with Autism Spectrum Disorder at diagnosis and beyond. *Social Work in Mental Health*, 10, 311- 330. DOI: 10.1080/15332985.2012.664487.
- Myers, B. J. (2009). My Greatest Joy and My Greatest Heart Ache: Parents' own words on how having a child in the autism spectrum has affected their lives and their families' lives. *Research in Autism Spectrum Disorders*, 3, 670–684. Doi: 10.1016/j.rasd.2009.01.004.
- Patton, M. Q. (2002). *Qualitative Research and Evaluation Methods*. (3<sup>rd</sup> ed.). California: SAGE Publications.
- Poslawsky, I. E., Naber, F. B. A., Van Daalen, E., & Van Engeland, H. (2014). Parental Reaction to Early Diagnosis of their children's Autism Spectrum Disorder: An Exploratory Study. *Child Psychiatry Human Development*, 45, 294- 305. doi: 10.1007/s10578-013-0400-z.
- Pozo, P., Sarria, E., & Brioso, A. (2011). Psychological adaptation in parents of children with autism spectrum disorders. In M. R. Mohammadi (Ed.), *A comprehensive book on Autism Spectrum Disorders*. (pp. 107-130). Rijeka, Croatia: InTech Open Access.

- Pozo, P., Sarria, E., & Mendez, L. (2006). Estrés en madres de personas con trastornos del espectro autista [Stress in mothers of people with autism spectrum disorder]. *Psicothema*, 18, 342-347, ISSN: 0214-9915.
- Rogers, M. L. (2008). Can marital satisfaction of parents raising children with autism be predicted by child and parental stress. *ProQuest Dissertation and Theses*, 0451 (1389).
- Siegel, B. (1997). Coping with the Diagnosis of Autism, in D.J. Cohen & F. R. Volkmar (eds) *Handbook of Autism and Pervasive Developmental Disorder*, pp. 745-66. New York: Wiley.
- Shulman, L. (1992). *The skills of helping individuals, families and groups* (3<sup>rd</sup> ed.). Itasca, Illinois Boston University, School of Social Work, F.E. Peacock Publisher, Inc.
- Skellern, C., McDowell, M., & Schluter, P. (2005). Diagnosis of Autistic Spectrum disorder in Queensland: Variations in practice. *Journal of Paediatric Child Health*, 41. 413- 418. Doi:10.1111/j.1440-1754.2005.00667.x.
- Smith, B., Chung, M. C., & Vostanis, P. (1994). The Path to Care in Autism: Is it better now?, *Journal of Autism and Developmental Disorders*, 24, 551-564.
- Stainton, T. & Besser, H. (1998). The positive impact of children with an intellectual disability on the family. *Journal of Intellectual and Developmental Disability*, 23, 57-70.
- Tonge, B., Brereton, A., Kiomall, M., MacKinnon, A., King, N., & Rinehart, N. (2005). Effects on parental mental health of an education and skills training

program for parents of young children with autism: A randomized controlled trial. *The American Academy of Child and Adolescent Psychiatry*, 45, 561-569, DOI: 10.1097/01.chi.0000205701.48324.26.

Tuckett, A. G. (2004). Truth-telling in Aged Care: a Qualitative Study. Unpublished doctoral thesis. School of Public Health, Kelvin Grove: Queensland University of Technology.

Tuckett, A. G. (2005). Applying thematic analysis theory to practice: A researcher's experience. *Contemporary Nurse*, 19, 75-87. DOI:10.5172/conu.19.1-2.75.

Veness, C., Prior, M., Bavin, E., Eadie, P., Cini, E. & Reilly, S. (2012). Early indicators of autism spectrum disorder at 12 and 24 months of age: a prospective, longitudinal comparative study. *Autism*, 16, 163-177. Doi: 10.1177/1362361311399936.

Wachtel, K., & Carter, A. S. (2008). Reaction to diagnosis and parenting styles among mothers of young children with ASDs. *Autism*, 12, 575- 594. DOI: 10.1177/13623613080994505.

Warren, Z., McPheeters, M. L., Sathe, N., Foss-Feig, J. H., Glasser, A., & Veenstra-VanderWeele, J. (2011). A systematic Review of Early Intensive Intervention for Autism Spectrum Disorders. *Paediatrics*, 127, 1303- 1314, doi:10.1542/ped.2011-0426.

Weiss, J. A., MacMullin, J. A., & Lunsky, Y. (2014). Empowerment and parent gain as mediators and moderators of Distress in Mothers of children with Autism Spectrum Disorders. *Journal of Child and Family studies*, 24, 2038-2045. DOI 10. 1007/s10826-014-0004-7.

Woodgate, R. L., Ateah, C., & Secco, L. (2008). Living in a world of our own: the experience of parents who have a child with autism. *Qualitative Health Research, 18*, 1075- 1083. DOI: 10.1177/1049732308320112.

Wright, K. (2000). Computer-mediated social support, older adults and coping. *Journal of Communications, 50*, 100-118.

## Appendix A

### *Recruitment Letter*





We see the ability within.

**Launceston**

65 Amy Rd Newstead  
PO Box 416 Launceston TAS 7250  
P 03 6345 7333  
E [society@stgiles.org.au](mailto:society@stgiles.org.au)

**Hobart**

11a Gant St Lenah Valley  
PO Box 45 New Town TAS 7008  
P 03 6238 1888  
E [adminsouth@stgiles.org.au](mailto:adminsouth@stgiles.org.au)

[stgiles.org.au](http://stgiles.org.au)

1300 278 445 | 1300 2stgiles

May 7, 2015

Dear (potential participant)

We are writing to you to invite you to participate in a study conducted by the University of Tasmania on factors associated with parental adaptation during the Autism Spectrum Disorder diagnosis process. We are especially looking at the diagnostic process used by St Giles Developmental Assessment Team and how you found this process to be helpful or unhelpful.

You will be asked to participate in an approximate one hour interview and given the chance to reflect upon your experiences and add your opinions to the evaluation of services for you and your child. The information sheet attached should provide you with a better overview of the project.

If you have any questions about the study, or would like to arrange a time for an interview at a time convenient to you, please contact our researcher using the details below.

Jozie de Deuge

Ph: 0400 836 515

Email: [jksmith0@utas.edu.au](mailto:jksmith0@utas.edu.au)

Kind Regards,

## Appendix B

### *Consent Form*



## CONSENT FORM

Title of Project: Factors Associated with parental adaptation during the Autism  
Diagnostic journey

- 
1. I have read and understood the 'Information Sheet' for this project.
  2. The nature and possible effects of the study have been explained to me.
  3. Any questions that I have been asked have been answered to my satisfaction.
  4. I understand that the study involves an approximate 1 hour interview.
  5. I understand that a transcript of my interview will be sent out to me to review and make alterations if I request, with a two week turn around date.
  6. I understand that if at any stage I become distressed during the interview appropriate support will be made available.
  7. I understand that the interview will be audio taped and transcribed verbatim and that these will be stored separately in locked cabinets at the School of Psychology at the University of Tasmania, Launceston for a period of five years following the publication, after which they will be destroyed.
  8. I understand that at the conclusion of the study I will be able to collect a summary of the results of the overall study to from St Giles, Launceston.
  9. I agree that the research data gathered from me for the study may be published in an Honours in Psychology research thesis by Mrs Jozie de Deuge provided that I cannot be identified as a participant.
  10. I understand that the researchers will maintain my identity confidential and that any information I supply to the researcher(s) will be used only for the purpose of the research
  11. I agree to participate in this investigation and understand that I may withdraw at any time without any effect, and if I so wish, may request that any data I have supplied to date be withdrawn from the research.

Name of participant:

---

Signature:

Date:

Appendix C  
*Information Sheet*



**Factors Associated with parental adaptation during  
the Autism Diagnostic Journey**

## **Information Sheet for Parents or Carers**

### **Invitation**

You are invited to participate in a research study examining the parental experience of the Autism Spectrum Disorder (ASD) diagnosis process. The objective of the research is to identify factors that influence how parents/ caregivers of children who may or who have already received an ASD diagnosis cope with and adapt to this experience. We are particularly interested in finding out about what helps you deal with all aspects of the diagnostic process. This study is being conducted in partial fulfilment of a Bachelor of Behavioural Science Honours degree for Jozie de Deuge under the supervision of Professor Douglas Paton of the School of Psychology (University of Tasmania) and Dr Lyndsay Quarmby, Clinical Psychologist at St Giles and Lecturer in Rural Health (University of Tasmania), Launceston.

### **What is the purpose of this study?**

The purpose of this study is to investigate the experiences of mothers who have had a child who are currently waiting or have gone through the assessment process with the Developmental Assessment Team (DAT) at St Giles, Launceston for an Autism Spectrum Disorder and consequently received an ASD diagnosis or are presenting with serious red flags. Within this study we want to identify adaptive issues that arise throughout the diagnostic process. The results of this study will allow us to develop a set of guidelines, and potential educational and training materials that can be used to facilitate positive adaptation and empowerment of parents throughout the ASD diagnostic process.

### **Why have I been invited to participate in this study?**

You have been invited to participate in this study as you have a child who is currently waiting to go through (or has recently gone through) the assessment process with the Development Assessment Team at St Giles Launceston.

### **What will I be asked to do?**

We would like you to participate in an approximately 1 hour interview with a member of our research team. We would like to find out more about your experiences through the ASD Diagnosis process, whether you are beginning this journey, have been through this process or received a diagnosis some time ago, and what you have found helpful or less helpful. If you agree to take part in an interview, a member of our team will phone you and arrange to meet you at a time and place convenient to you. If you would prefer, we can conduct the interview over the phone at a time convenient to you.

The interviews will be recorded (audio only) and a code will be assigned. The interviews will then be transcribed into text, ensuring we have all the information you have provided. At that point the audio recording will be deleted. If you wish you may have a copy of the transcription and request changes.

### **Are there any possible benefits from participation in this study?**

You will receive a copy of a summary of the report on adaptive strategies and have information on how this model of diagnosis has contributed to your adaptation. You will also have the opportunity to reflect on your experiences and add your opinions to the evaluation of services for you and your child. The care you currently receive will not be affected whether you take part in this study or not. The study is being conducted to find out how the parents of the child diagnosed with ASD, find the diagnostic process, and factors that affect a parent's adaptation to this diagnosis. Information will be provided to St Giles policy makers to help inform how they can better enhance their services as a result of these findings.

### **Are there any possible risks from participation in this study?**

The risk to participants is limited. It is possible that you may find some of the questions difficult to answer and in the unlikely event this occurs and you're experiencing any feelings of distress we will be able to refer you to a St Giles psychologist who will be on standby and available to consult with you.

### **What if I change my mind during or after the research?**

As a voluntary participant in this study you are free to withdraw at any time without explanation. Simply contact a member of the research team on the phone number or email listed at the bottom of this page. Any information you have provided to the research team prior to your withdrawal can be deleted from the dataset.

### **What if I have questions about this research?**

If you would like to discuss any aspect of this study please feel free to contact Professor Douglas Paton on ph (03) 6324 3193 or Jozie de Deuge on ph: 0400836515 who would be happy to answer any questions you may have. You will be able to obtain a copy of the report on the findings of this project from St Giles on completion of the project from St Giles on completion of the project (end of October).

This research has been approved by the Tasmanian Social Science Human Research Ethics Committee. If you have concerns or complaints about the conduct of this study, please contact the Executive Officer of the HREC (Tasmania) Network on (03) 6226 7479 or email [human.ethics@utas.edu.au](mailto:human.ethics@utas.edu.au). The Executive Officer is the person nominated to receive complaints from research participants. Please quote ethics reference number H14828.

**Thank you for taking the time to consider this study.**

**If you wish to take part in it, please sign the attached consent form.**

**Please remember to keep this information sheet for future reference.**

Jozie de Deuge

Student Researcher

Ph:

Email: [jksmith0@utas.edu.au](mailto:jksmith0@utas.edu.au)

## Appendix D

### *Interview Schedule*



## Factors Associated with parental adaptation during the Autism Diagnostic journey

### Interview Questions

\*\* Interview will also be guided by the interviewee's response

1. At what stage did you first have concerns for your child's development and what were these concerns around? Can you describe the events and circumstances that led to your being concerned about your child's well-being?
2. How long after you had concerns did you take action? What led you to decide to take action and why?
3. How were your concerns met by the first professional you approached? Can you describe your experience of your initial interaction with XXX professionals?
4. At what stage were you referred to St Giles? Please describe what happened (and why) next and what that meant for you/ family and your child
5. How long were you/ have you been on the waiting list, and what kind of information were you given at this stage?
6. What/ who was helpful or unhelpful during this period?
7. How did you find the assessment process? Please describe your experience of the assessment processes?
8. What improvements would you recommended to the clinicians and of the diagnosis process? What aspects helped/ hindered your dealing with the outcome of the processes.
9. What affect has the diagnosis had upon your life? Financial? Relationships? Please describe the implications... this has had for you, your family and your child.



## Appendix E

*University of Tasmania Ethics Approval*

Social Science Ethics Officer  
 Private Bag 01 Hobart  
 Tasmania 7001 Australia  
 Tel: (03) 6226 2763  
 Fax: (03) 6226 7148  
 Katherine.Shaw@utas.edu.au




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HUMAN RESEARCH ETHICS COMMITTEE (TASMANIA) NETWORK

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08 May 2015

Professor Douglas Paton  
 Psychology  
 Private Bag 1342

*Sent via email*

Dear Professor Paton

Re: FULL ETHICS APPLICATION APPROVAL  
 Ethics Ref. H0014828 - Factors Associated with parental adaption during the Autism  
Diagnosis process

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We are pleased to advise that the Tasmania Social Sciences Human Research Ethics Committee approved the above project on 06 May 2015.

This approval constitutes ethical clearance by the Tasmania Social Sciences Human Research Ethics Committee. The decision and authority to commence the associated research may be dependent on factors beyond the remit of the ethics review process. For example, your research may need ethics clearance from other organisations or review by your research governance coordinator or Head of Department. It is your responsibility to find out if the approval of other bodies or authorities is required. It is recommended that the proposed research should not commence until you have satisfied these requirements.

Please note that this approval is for four years and is conditional upon receipt of an annual Progress Report. Ethics approval for this project will lapse if a Progress Report is not submitted.

The following conditions apply to this approval. Failure to abide by these conditions may result in suspension or discontinuation of approval.

1. It is the responsibility of the Chief Investigator to ensure that all investigators are aware of the terms of approval, to ensure the project is conducted as approved by the Ethics Committee, and to notify the Committee if any investigators are added to, or cease involvement with, the project.
2. Complaints: If any complaints are received or ethical issues arise during the course of the project, investigators should advise the Executive Officer of the Ethics Committee on 03 6226 7479 or [human.ethics@utas.edu.au](mailto:human.ethics@utas.edu.au).

A PARTNERSHIP PROGRAM IN CONJUNCTION WITH THE DEPARTMENT OF HEALTH AND HUMAN SERVICES

3. Incidents or adverse effects: Investigators should notify the Ethics Committee immediately of any serious or unexpected adverse effects on participants or unforeseen events affecting the ethical acceptability of the project.
4. Amendments to Project: Modifications to the project must not proceed until approval is obtained from the Ethics Committee. Please submit an Amendment Form (available on our website) to notify the Ethics Committee of the proposed modifications.
5. Annual Report: Continued approval for this project is dependent on the submission of a Progress Report by the anniversary date of your approval. You will be sent a courtesy reminder closer to this date. **Failure to submit a Progress Report will mean that ethics approval for this project will lapse.**
6. Final Report: A Final Report and a copy of any published material arising from the project, either in full or abstract, must be provided at the end of the project.

Yours sincerely

Natasha Jones  
Ethics Officer  
Tasmania Social Sciences HREC

## Appendix F

*Letter of support from St Giles*

13<sup>th</sup> February 2015

Research Integrity and Ethics Unit  
Office of Research Services  
University of Tasmania  
Private Bag 01  
Hobart Tas 7001

To whom it may concern,

I am writing to confirm the support of St Giles to undertake collaborative research with the University of Tasmania, specifically as it relates to Jozie De Deuge's proposed Honours (Psychology) research project exploring parental adjustment prior to and following an Autism Spectrum Disorder diagnosis. Furthermore, we are pleased to support Jozie as she also holds a casual employment position at St Giles.

The Manager of Diagnostic and Support Services contacted the UTAS Psychology Department with this specific project idea due to its clinical relevance and need within her department. Having a greater understanding of the factors that influence families and their participation with our organisation will better equip us to respond in a more efficient and family centred manner.

St Giles is committed to assisting the University of Tasmania with external supervision, access to participants and have Psychology staff that would be available to the student and clients should this be required during the course of her interviewing.

We look forward to collaborating with Psychology department on this project.

Kind Regards,

pp

Ian Wright  
Chief Executive Officer  
St Giles Society

## Appendix G

### *Interview Transcripts CD*